


## Proclamation Request Form

Requests for the issuance of proclamations are governed by Council Policy (excerpted below). Requests must be received at least six (6) weeks in advance of the requested issuance date and may be emailed to the City Clerk at [ClerksApprovalRequests@london.ca](mailto:ClerksApprovalRequests@london.ca) or mailed to City Hall, P.O. Box 5035 LONDON, ON, N6A 4L9.

### Request details

Name of Organization GBS-CIDP Foundation of Canada
Date Proclamation Required May 2022
Proclamation Name Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month
Proclamation Type (day, week or month) Month
Category (public awareness campaigns), (charitable fundraising campaigns), (arts and cultural celebrations) Public awareness campaign
Requester Name Darryl Bedford
Requester Email Address dbedford@gbscidp.ca
Requester Address London, ON N5Z 2C1
Provide details of your Organization's Connection to London See letter: Importance of University Hospital Department of Neurology and Western University in the diagnosis, treatment, and research into GBS, CIDP, and variants.
Required Supporting Documents <ul style="list-style-type: none"><li>• Detail information on the Organization</li><li>• Detail information on the Event</li><li>• Confirmation of authorization from the Organization to submit the request</li></ul>
The undersigned confirms that I am the Official Representative of the Organization requesting the Proclamation and that by signing this Application, I acknowledge and agree that my organization complies with all City of London's Policies and By-laws  Signature  Date March 1, 2022
NOTICE OF COLLECTION OF PERSONAL INFORMATION  Personal information collected on this form is collected under the authority of the <i>Municipal Act, 2001</i> , S.O. 2001, c. 25 and may also be used for purposes related to the Issuance of Proclamations Policy and Proclamation Request Form. Questions about this collection should be addressed to the City Clerk, 3rd floor, City Hall, 300 Dufferin Ave., London, ON N6A 4L9. Tel: 519-661-2489, ext. 4937, email: <a href="mailto:csaunder@london.ca">csaunder@london.ca</a>



# GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome/Chronic Inflammatory Demyelinating Polyneuropathy  
*Support, Education, Research, Advocacy*

**Honorary Board**  
Larry Brenneman (*deceased*)  
Tom Feasby, MD  
Susan Keast  
Serge Payer  
Kenneth Shonk, MD

**Executive Director**  
Donna Hartlen

**Officers**  
Darryl Bedford  
*President*  
Howard Huss  
*Treasurer*

**Board of Directors**  
Darryl Bedford  
Holly Gerlach  
Alexandre Grant  
Howard Huss  
Dean Lower  
Pamela Stoikopoulos  
Demetrios Strongolos  
Ron Van Holst

**Medical Advisory Board**  
Steven Baker, MD  
Brenda Banwell, MD  
Timothy Benstead, MD  
Pierre Bourque, MD  
Vera Bril, MD  
Colin Chalk, MD  
Kristine Chapman, MD  
Angela Genge, MD  
Gillian Gibson, MD  
Angelika Hahn, MD  
Hans Katzberg, MD  
Kurt Kimpinski, MD  
Rami Massie, MD  
Elizabeth Pringle, MD  
Zaeem Siddiqi, MD  
Jiri Vajsar, MD  
Chris White, MD  
Douglas Zochodne, MD

March 1, 2022

City Clerk  
City of London  
PO Box 5035  
London, ON  
N6A 4L9

Sent by e-mail: ClerksApprovalRequests@london.ca

This letter is in support of our application to proclaim May 2022 as GBS and CIDP Awareness Month in the City of London.

Though it has been difficult to raise awareness during this global pandemic, we are very grateful for the proclamations that your Council issued in 2020 and 2021 and we hope to build on that.

## 1) Detailed Information on the Organization

The GBS/CIDP Foundation of Canada is a national, not-for-profit patient organization that supports patients and families afflicted with Guillain-Barre Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, and variants such as Multifocal Motor Neuropathy. These are rare autoimmune disorders where the body's immune system attacks the myelin sheath that protects the periphery nerves. GBS has a sudden onset of symptoms, which can cause complete paralysis within a day. With an early diagnosis and prompt treatment, patients can recover, but are generally left with varying residual effects. Recovery and rehabilitation can take months or longer. CIDP is the chronic form of the condition with a slower progression that requires long term treatment for patients to reduce the chances of permanent nerve damage.

The Foundation serves patients through support, education, research and advocacy. For further details, visit [www.gbscidp.ca](http://www.gbscidp.ca)

Canadian charity registration number: 887327906RR0001

You are welcome to use or adapt the following WHEREAS clauses in your motion:

WHEREAS, the Month of May has been internationally designated as "GBS and CIDP Awareness Month" to educate the public and to focus attention on Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), rare, paralyzing and potentially catastrophic disorders of the peripheral nerves; and

WHEREAS Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and their variants such as Multifocal Motor Neuropathy (MMN), are rare conditions which are paralyzing and potentially catastrophic inflammatory disorders of the peripheral nerves, which can be characterized by rapid onset of weakness and, often, paralysis of the legs, arms, breathing muscles and face, in some cases leading to complete paralysis and requiring life-sustaining hospital care, and

WHEREAS the cause of GBS, CIDP, and MMN is unknown, and these conditions can develop in any person, regardless of age, gender, or ethnic background, and

WHEREAS GBS, CIDP, and MMN have a slow and unpredictable recovery, patients, and their families face an uncertain future, usually requiring months of hospital care without knowing if or when they will recover, or whether they will face long-term disabilities. Earlier diagnosis, treatment, and access to rehabilitation services can improve the chances of avoiding permanent lifelong residual damage of the nerves, and

WHEREAS in 2003, GBS/CIDP Foundation of Canada, a patient organization was founded to provide support, education, research, and advocacy, was founded so that no patient or family would go through GBS, CIDP, MMN or their variants alone,

THEREFORE BE IT RESOLVED that...

### Connections to London

In my previous proclamation requests, I noted the important role London's own LHSC University Hospital and Western University have in the diagnosis, treatment, and research into this family of conditions.

London is also an important plasma donation site for Canadian Blood Services. Londoners should visit [www.blood.ca](http://www.blood.ca) for more information on how to donate. Blood plasma is needed to manufacture immunoglobulin (Ig), a primary treatment for these conditions. Depending on the quality of the plasma, it may require over a thousand donors just to manufacture enough Ig to treat one patient. And for conditions such as CIDP or MMN, treatment may need to be repeated every 3 to 4 weeks, sometimes for life.

As I noted in our previous requests, as a Londoner I am the President of the Board of Directors for the Foundation and a CIDP patient myself.

### 2) Detailed information on the Event

We are working to raise awareness of these rare conditions so that future patients get help sooner and will know that our organization is here to provide hope. We provide support and information through trained volunteers, our website, materials provided to hospitals, and organize local and online peer-to-peer support meetings. We provide patient educational events and build awareness within the medical

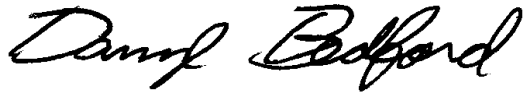
community. We advocate for access to diagnosis and appropriate treatment, and we support Canadian research that aims to improve the quality of life of GBS, CIDP, and MMN patients.

### 3) Confirmation of Authorization to Submit the Request

As President of the Board of Directors, I am authorized to submit this application on behalf of the Foundation.

Finally, we wish to thank City Council for their recognition of our Foundation and work with last year's proclamation. We look forward to the City's continued support of our activities.

Sincerely,

A handwritten signature in black ink that reads "Darryl Bedford". The signature is written in a cursive, flowing style.

Darryl Bedford  
President, Board of Directors (London, Ontario)  
GBS-CIDP Foundation of Canada



## Mission :

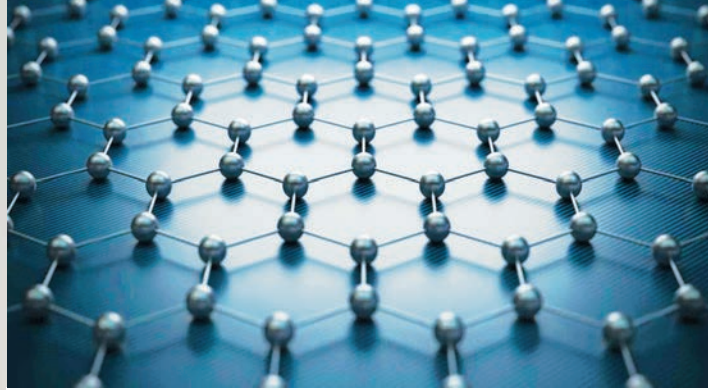
To engage in advocacy, including treatment access, (at the federal, provincial and grassroots levels) to improve the quality of life for individuals and families affected by GBS, CIDP, or variants such as MMN.

## Vision :

Every person affected by GBS, CIDP, or variants such as MMN, will have access to early and accurate diagnosis, expert interdisciplinary treatment and support, and through continued research, a cure will be developed.

**GBS/CIDP Foundation of Canada** is a registered Canadian charity. Our foundation is made up of trained caring volunteers who have had GBS, CIDP, and variants, who are dedicated to the support of our patient community in hopes that no patient goes through these disorders alone.

If you or someone you know would like more information, please contact the foundation. Medical professionals are welcome to contact us for literature and to get more information on how to connect your patients with the foundation.



*For more information, please contact:*

*Support • Education • Research  
• Advocacy*



GBS/CIDP Foundation of Canada  
3100 Garden Street  
PO Box 80060 RPO Rossland Garden  
Whitby, ON L1R 0H1

1(647) 560-6842  
[info@gbscidp.ca](mailto:info@gbscidp.ca)  
[www.gbscidp.ca](http://www.gbscidp.ca)

*The foundation is extremely fortunate to have the commitment and expertise of dedicated neurologists that are on our Medical Advisory Board. For a list, visit [www.gbscidp.ca](http://www.gbscidp.ca).*

Find us on :



Charity Registration: 887327906RR0001

## Guillain-Barré Syndrome

## Chronic Inflammatory Demyelinating Polyneuropathy

## Multifocal Motor Neuropathy

## Miller Fisher Syndrome & variants



## Guillain-Barré Syndrome (GBS)

is an inflammatory disorder of the peripheral nerves, those outside the brain and spinal cord. Rapid onset of weakness and often paralysis of the legs and arms within a few weeks of onset accompany this disorder. Back pain or pain in the extremities as well as numbness and tingling can also be part of the initial presentation. Patients during early days of onset may require intensive care to monitor breathing and other body functions. Rehabilitation helps during the recovery phase, which can take months or even years. GBS can affect any person, at any age, of either gender, or any ethnic background. **Miller Fisher Syndrome (MFS)** is a variant of GBS which also presents rapidly and affects the peripheral nerves. However, MFS more commonly causes unsteadiness and imbalance and affects the eye muscles causing double vision, visual blurring or droopy eyelids.

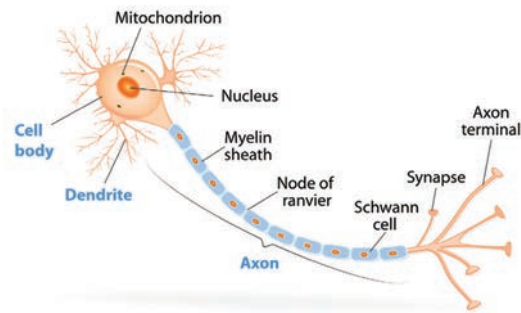


### Treatments :

- High dose of intravenous immunoglobulin (IVIG)
- Plasma Exchange

## Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

is an inflammatory disorder of the peripheral nerves. There is increasing weakness as well as numbness and tingling of the legs and arms that can develop over a period of a few months and symptoms continue if untreated. It is caused by damage to the covering of then nerves, called myelin. If treated early and aggressively, therapies can limit the damage to the nerves and contribute to a better quality of life. Like GBS, CIDP can start at any age, and with either gender.



## Acquired Motor Sensory Neuropathy (AMSAN)

, also known as Lewis Sumner Syndrome is often considered a variant of CIDP. It shares many features with CIDP but typically has a more asymmetric (more side to side differences), and multifocal (specific areas affected) presentation compared to patients with CIDP.

### Treatments :

- Immunotherapies, (IVIG, SCIG)
- Plasma Exchange
- Prednisone
- Immunosuppressives

## Multifocal Motor Neuropathy (MMN)

is an inflammatory nerve disease affecting the myelin sheath, or the insulation of nerves, similar to CIDP and GBS. It typically has a slow course over many years and affects the arms with weakness in the muscles that bend the fingers, however any nerve and muscle group can be affected. On nerve testing (EMG), "blocking" of the responses to the nerves that go to the muscles is seen. Sometimes, antibodies to a molecule called GM1-ganglioside are present and can be detected with additional testing. This can help with the diagnosis.

### Treatments :

- Immunotherapies, such as IVIG
- Plasma Exchange
- In contrast to CIDP, MMN is not usually responsive to medications such as prednisone or other immunosuppressives

### Services Available :

- Hospital visitation by knowledgeable volunteers
- Telephone support
- Local support group meetings
- Educational material
- Names of physicians specializing in the disorders
- Educational presentations
- Newsletters
- National & Regional Conferences
- Research funding
- Patient advocacy
- Awareness events
- Patient stories